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**Title:**

Fetal Medicine Specialists' experiences of providing a new service of termination of pregnancy for fatal fetal anomaly: A qualitative study

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**Running title:** Fetal Medicine Specialists and fetal anomalies

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## Abstract

**Objectives:** To explore fetal medicine specialists' (FMS) experiences of caring for parents following a fatal fetal anomaly (FFA) diagnosis, during the implementation of termination of pregnancy for fatal fetal anomaly (TOPFA) for the first time.

**Design:** Qualitative study.

**Setting:** Fetal medicine units in the Republic of Ireland.

**Population:** Ten FMS from five of the six fetal medicine units.

**Methods:** NVivo12 assisted in the thematic analysis of semi-structured in-depth face-to-face interviews.

**Main outcome measures:** FMS experiences of prenatal diagnosis and holistic management of pregnancies complicated by FFA

**Results:** Four themes were identified; 'not fatal enough', 'interactions with colleagues', 'supporting pregnant women' and 'internal conflict and emotional challenges'. FMS feared getting a FFA diagnosis incorrect due to the media scrutiny and criminal liability associated with the TOPFA legislation. Challenges with the ambiguous and 'restrictive' legislation were identified that 'ostracised' severe anomalies. Teamwork was essential to facilitate opportunities for learning and peer support. However, conflict with colleagues was experienced regarding diagnosis of FFA, provision of feticide and palliative care to infants born alive following TOPFA. Participants reported challenges implementing TOPFA, including the absence of institutional support and 'stretched' resources. FMS experienced internal conflict and a psychological burden providing TOPFA, but did so to 'provide full care for women'.

**Conclusions:** Our study identified challenges regarding the suitability of the Irish legislation for TOPFA and its rapid introduction into clinical practice. It illustrates the importance of institutional and peer support as well as the need for supportive management in the provision of a new service.

**Funding:** None

**Keywords:** Maternity Services, fetal medicine and surgery, termination of pregnancy, medical law, qualitative research

**Tweetable abstract:** The implementation of termination services for fatal fetal anomaly is complex and requires institutional support.

Accepted Article

## Introduction

Approximately 3% of pregnancies receive a diagnosis of a major congenital anomaly<sup>1</sup> and more women now receive a diagnosis of a fetal anomaly during pregnancy due to advancements in prenatal testing.<sup>2</sup> Such a diagnosis creates much uncertainty regarding the fetal prognosis and<sup>3,4</sup> parents face many difficult decisions, primarily whether to terminate or continue with the pregnancy.<sup>5</sup>

Universal access to reproductive healthcare and safe abortion has long been advocated for as a woman's human right,<sup>6-8</sup> resulting in countries reforming laws to facilitate and broaden abortion services.<sup>9,10</sup> The Republic of Ireland legislated for termination of pregnancy (TOP) for fatal fetal anomaly (FFA) for the first time in 2018. Prior to this, Ireland held one of the most restrictive legislative positions on abortion in the world<sup>11</sup>; the Eighth Amendment of the Constitution protected "the right to life of the unborn"<sup>12</sup> and ensured that abortion, including TOP for FFA, was a criminal offence.<sup>13,14</sup> On January 1, 2019, the Health (Regulation of Termination of Pregnancy) Act 2018 was enacted, permitting TOP if two medical practitioners (one being an obstetrician), 'are of the reasonable opinion' that the fetal diagnosis is 'likely to lead to the death of the fetus' during the pregnancy or in the first 28 days of life.<sup>15</sup> TOP without provisions of the legislation was retained as a criminal offence. A fetal-medicine specialist usually makes or confirms a diagnosis and approves the request for TOP for FFA. The Irish Interim Clinical Guideline for TOP for FFA recommends that discussions with the fetal medicine multidisciplinary team (see Appendix S1 for suggested members) regarding the diagnosis and prognosis should form a component of the assessment of fetal anomalies.<sup>16</sup>

There is little qualitative research, however, on the lived experience of fetal-medicine specialists, (FMS) who are involved in prenatal diagnosis, counselling and care of pregnancies complicated by FFA. This study aimed to explore FMS experiences in caring for women diagnosed with a FFA during a change in service provision for TOP for FFA.

## Methods

A qualitative research design was utilised as it facilitated interpretation of how people make sense of their lived experience.<sup>16,17</sup> This methodology facilitated the researcher to examine FMS experiences of changing practice of caring for parents who receive a FFA diagnosis following the implementation of TOP for FFA. Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No. ECM 4 (gg) 12/02/19).

Purposive sampling was implemented to ensure only those currently practising as FMS following specialist training were recruited. Members of the national Fetal Medicine Working Group were approached by KOD to facilitate communications from SP about the study. SP provided participant information leaflets to twelve FMS and encouraged them to share study information with their FMS colleagues. The topic guide was developed by all three authors and input sought from members of the Pregnancy Loss Research Group, which include representatives of the multidisciplinary team (MDT) and service users.<sup>19</sup> No other input was sought from patient and public representatives. Data collection occurred between November 2019 and January 2020. Ten FMS, seven female and three male, with varying years of experience (presented in Table 1) and all specialty-trained outside Ireland, representing five of the six fetal medicine units in Ireland, participated in semi-structured face-to-face interviews. This represented over a third of the 27 FMS practising in Ireland with varied involvement in TOP. A topic guide was used to aid the interviews conducted by SP (Appendix S2). Interviews lasting from 36 to 71 minutes were recorded and transcribed verbatim by SP.

This study adopted a data analysis methodology based on the principles of thematic analysis.<sup>20</sup> The transcripts were read and reread to become familiarised with the data and identify initial codes. Further analysis facilitated the categorisation of codes through grouping the initial codes, developing them into potential themes and sub-themes and generated definitions and names for each theme. NVivo12 was utilised to assist in the analysis of the data and enhance this study's trustworthiness through acting as an audit trail. Data analysis was undertaken by SP and an external check on the analytical process and a consensus discussion regarding theme development with SM was undertaken. This practice is a helpful approach to encourage reflection of assumptions that unwittingly may have been overlooked.<sup>21-23</sup> Coding is a reflexive process that bears the mark of the researcher.<sup>21</sup> Reflexivity is essential as it enables the reader to assess the validity of qualitative analysis by understanding the composition of the research team responsible for its production.<sup>24</sup> SP is a Children's nurse undertaking a PhD in major fetal anomalies and SM is a social researcher with a PhD and 15 years' experience of conducting qualitative research. SP and SM had no relationship with any research participant prior to the interview. KOD did not actively participate in data collection or analysis due to her position as a FMS but did review the finalised themes for publication to further limit bias. Reflexive thematic analysis argues that meaning is generated through interpretation therefore, inhibiting the prediction of the number of data items or when to cease data collection.<sup>25</sup> Therefore, data were collected until no new themes were identified and inductive thematic saturation was perceived.<sup>25</sup>

No study funding to declare.

## Results

Four overarching themes emerged from the data; 'not fatal enough', 'interactions with colleagues', 'support for pregnant women' and 'internal conflict and emotional challenges', all with three subthemes each, as presented in Table 2. Direct quotes to support each theme are presented in Table 3 and Table 4.

### Not fatal enough

Patients' best interest motivated FMS to ensure a 'diagnosis is correct' and that they 'are doing everything to inform women and their partners'. FMS identified that 'where the default is termination is the worst outcome' it leaves them 'exposed', meaning if a TOP for FFA has been performed and the diagnosis is found to be incorrect, FMS feel vulnerable to prosecution and the media scrutiny that an incorrect diagnosis would create. As a result, over half of the participants shared their fear of getting the diagnosis wrong. They expressed 'anxiety' regarding permitting a TOP for the identified anomaly and the consequence 'if somebody doesn't agree' that it is fatal.

Half of the FMS expressed 'uncertainty' regarding a diagnosis being fatal as it 'depends' on an individual's 'definition' of what is fatal. Relating to prognosis, participants identified that 'there is never any certainty' when death will occur, that there is always an 'outlier' (a baby that will live longer than expected). A couple of FMS commented on the relief experienced when the baby dies, confirming their diagnosis was 'right'. Their fear of getting it wrong is associated with the 'difficult' legislation and that 'under the legislation, (they) can't have babies who survive for a long period of time', i.e. over the 28 days referenced within the legislation. Legislative challenges were identified by most participants, primarily, its ambiguity, 'understanding what the legislation allows for', what conditions are deemed fatal and therefore legally terminated. Over half of the participants referenced the legislation as 'restrictive' and argued that it was forcing them to travel for a TOP for conditions that are not 'quite fatal enough but are absolutely not going to survive'.

All FMS faced difficulty with conditions which were 'not clearly fatal but clearly awful'. They felt frustration in hearing these cases being referred to as 'severely fatal', having the potential to be fatal, and TOP not being 'sanctioned' if there was ever a survivor. Half of the FMS shared that the distinction



between fatal and severe resulted in women being 'ostracised' as only those with a fatal diagnosis can legally obtain a TOP in Ireland, while those with a severe diagnosis must travel for this service. These women are then open to 'societal questioning' and suggestions that they are travelling 'because it is not fatal enough, as maybe the baby could be okay'. Over half of the participants identified the 'complex' cases and the 'difficult decisions' of what conditions met the criteria within the legislation and felt the MDT was 'supportive' with their decision-making. MDT discussions gave FMS an opportunity to include other 'specialties' and 'experienced colleagues' to assist in their decision-making. However, some FMS expressed 'lament having to bring' discussions to the MDT as some disciplines were too 'vocal' and 'strong' with their 'anti-abortion' opinions.

### Interactions with colleagues

Almost all FMS identified that a good working relationship with MDT members was 'essential' to provide good quality care. Over half of the FMS identified midwives as 'essential'; they were 'more available' and 'better' in supporting women. Teamwork benefitted the FMS directly as local and national colleagues acted as both a source of learning and peer support. Nearly all FMS identified the need to 'debrief' with those who understand their challenges as 'very important' for their self-care. Despite identifying the need for collaborative working, nearly all participants experienced 'conflict' or 'opposition' when discussing the fatality of conditions. Half of the FMS described meetings as 'divisive' involving 'contentious cases'. They shared that there was 'a massive uncomfortableness' and 'suspicion' with TOP. Over half of the FMS experienced conflict with Neonatologists. Participants reported frustration that these colleagues would engage in decision-making for TOP for FFA but refuse to care for the woman and her baby 'if the driving force was termination'. This generated concern for FMS as they are 'unclear as to who will look after those babies' if a baby is born alive following TOP by induction of labour and without feticide, resulting in them 'begging people to help' them in providing palliative care.

This led to another challenge experienced by FMS: 'dare I say the word feticide'. Over half of the FMS experienced differences of opinion relating to feticide. Some participants expressed 'friction' with Neonatologists due to an expectation for 'universal feticide' to ensure no baby was born alive. Half of the FMS identified a 'role for feticide', 'depending on the anomaly' while some expressed that feticide needed to be mandatory for late gestations because it was in the best interest of the baby not to be born alive. A couple of FMS advocated that feticide should be a parental choice, and that the 'relatively tight definition' (Irish legislation) and 'small number of cases' dismissed it as a requirement.

Over half of the FMS experienced opposition with conscientious objectors. While acknowledging people's right to conscientious objection, they were frustrated with what they called 'conscientious obstruction'. Some felt treatment was delayed at times, for example where provision of TOP for FFA was limited to certain days. Others described the situation as 'tense', unsure of 'how far conscientious objection extended'. Where hospital management held a position of conscientious objection, participants expressed that this 'led to a lack of support of those working in this area'. These FMS expressed feelings of being 'undervalued' and lack of acknowledgement for the 'difficult' tasks associated with their role. Half of the participants shared feelings of disapproval and disrespect from local, national and retired colleagues.

Nearly all of the FMS experienced difficulties when implementing the TOP service. Half of the FMS reported that they had to self-prepare, alongside their colleagues, in the absence of institutional support. An unsupportive environment resulted in FMS feeling unable to 'ask for help' while 'providing a new service with no new colleagues' with an 'increased workload'. These FMS acknowledged that while a small number, these cases take up 'a lot more time' and can require multiple visits. The few FMS who had organisational support reported positive experiences with the implementation of TOP for FFA. Despite their initial challenges, it 'bedded in' and became 'normalised'.

#### Support for pregnant women

Nearly all FMS shared the need to give parents a 'warning shot that something's not okay' when diagnosing a FFA. A warning shot enabled FMS to encourage women to have support when receiving a diagnosis of a FFA as some participants expressed difficulties when informing women of a FFA when alone. Half of the FMS suggested that they found it beneficial to allow time between appointments following the 'warning shot' as it enables 'much more meaningful discussion' about the diagnosis at the next visit. Over half of the participants identified the need to choose language 'carefully' based on their patient's 'health literacy', to 'pitch' it at a level they understand to ensure that the diagnosis is 'clear for people'.

Nearly all participants identified the importance of follow-up care and over half provided 'open access' for parents, where if needed, they could return to their clinic at any time. Additionally, over half provided care for the parents during their subsequent pregnancy, with a few wanting to see these women have a 'nice outcome' and get 'through' the experience of a FFA.

## Internal conflict and emotional challenges

Internal conflict was experienced by almost all FMS as a result of caring for women with a FFA, they expressed having 'a line' that they 'do not cross', and that the condition being terminated is a 'significant abnormality'. Over half of the FMS expressed internal conflict due to the provision of feticide and the need to 'separate yourself from it completely'. They described feticide as 'brutal', 'awful' and 'emotionally difficult' referring to it as 'stabbing the baby in the heart' and held themselves responsible for the death of the baby: 'I caused the death'. However, almost all FMS justified providing TOP for FFA or feticide because it was a 'kindness in some cases' and they would want someone to 'step up and just be kind'. FMS felt obliged to provide TOP for FFA as it is 'the right thing to do' and expressed the importance of being in a position to 'provide full care for women'.

Providing TOP for FFA created a 'psychological burden' for over half of the FMS. A couple referred to themselves as 'doctor death', dealing with death and dying or with opinions from others that they 'are trying to terminate everything'. Half of the participants expressed that this however was their job, that they have 'chosen' 'to support (parents)' and 'it's important to do it well'.

## Discussion

### Main Findings

This study, within an Irish context where TOP for FFA is being provided for the first time following an Electoral Referendum, identified fears of FMS working in prenatal diagnosis due to the potential for media scrutiny and criminal liability if a fetal condition terminated was not deemed to be a FFA. They expressed challenges resulting from the rapid introduction of the new TOP services, such as being unprepared or unsupported by their institution and working with difficult legislation and an increased workload. While they recognised teamwork as essential, conflict and opposition was widespread within their practice, due to differences of opinion regarding what qualifies as a FFA and the practice of feticide. Internal conflict and psychological burden among FMS providing TOP for FFA was highlighted, but FMS identified services needed to be provided and supporting parents motivated them to develop these services.

### Strengths and Limitations

A potential limitation of this study is that the participants self-selected to be a part of this study. Thus, it is possible that those who participated were influenced by personal agendas which potentially may have influenced the content of their interviews. Nonetheless, this study is the first to explore experiences of FMS during a significant national change in service provision for TOP for fetal anomaly.

## Interpretation

Within this study, FMS expressed fear of media scrutiny and being questioned on their diagnosis of FFA. Irish media regularly reports on adverse obstetric events suggesting mismanagement and names clinicians involved<sup>19</sup>, as was evident within weeks of introducing TOP services.<sup>27</sup> Such media attention can have a negative impact on healthcare professionals and parents.<sup>28, 29</sup> FMS fears stemmed from the 'difficult legislation' and the various definitions of what constitutes a FFA. Such definitions do not accurately describe many of the conditions associated as a FFA, as known survivors are linked to many of these conditions.<sup>30,31</sup> Additionally, diagnosing conditions as FFA in accordance with the Irish legislation is complex as many anomalies in isolation may not be considered a FFA however, when combined are potentially fatal.<sup>30</sup>

FMS within this study shared experiences of opposition from colleagues relating to decision-making on the fatality of conditions. Dommergues et al. (2010) suggests, in all countries where TOP for FFA is legalised, interpretation of the legislation is feasible.<sup>32</sup> Where criminal liability of clinicians exists, as it does in Ireland, the UK and throughout the US,<sup>33</sup> there is a potential for conservative interpretations of legislation leading to service provision inconsistencies.<sup>34</sup> Power et al. (2020) identified the need for a universal definition, to include an accurate description of a FFA that results in perinatal death to aid diagnosis, reduce subjectivity and standardise healthcare provision.<sup>30</sup> Furthermore, FMS described Neonatologists' refusal to provide perinatal palliative care to the baby following a TOP by induction of labour and without feticide, with some of the FMS sharing pressures experienced from Neonatologists to conduct feticide. FMS identified these experiences as a source of tension and conflict as they identified that in the absence of universal feticide, perinatal palliative care is warranted for these cases, but are left 'begging' for support to ensure its delivery. While the majority of TOP for FFA occur within the second trimester, before viability<sup>35</sup>, unfortunately, some pregnant women within Ireland are without universal access to anomaly scans and so are at risk of a late diagnosis.<sup>13,36</sup> Additionally, Ireland's legislation is without gestational limits and so creating the opportunity for late TOP for FFA. However in other jurisdictions feticide is not a legal requirement, unless requested by the parents, for fetal anomalies not compatible with survival.<sup>37</sup> Despite this, approximately 1-2% of UK terminations in 2018 were confirmed having no feticide<sup>38</sup>. FMS within this study expressed internal conflict regarding TOP for FFA and in particular, around feticide. The balancing of moral and ethical beliefs is universally identified among FMS providing TOP<sup>39-41</sup> and Obstetricians throughout Europe acknowledge the need for more resources and emotional support when providing late TOP.<sup>42</sup>

The complexity of introducing a national abortion service warrants the need for regulations, clinical guidance and protocols, and similar to other new services requires a well-developed plan supported by management.<sup>43</sup> Despite this being best practice, Irish clinical guidelines for the service delivery of TOP for FFA were rapidly developed during the introduction of the service.<sup>13</sup> FMS experiences identified offer learning for abortion providers in Northern Ireland during their current efforts to reform their abortion laws<sup>44,45</sup> and countries like Turkey, India and US where TOP for FFA is legalised but there are access restrictions.<sup>46,47</sup> The retention of criminal liability can have negative implications for health outcomes and limits clinicians in providing medical services that comply with professional and ethical standards of care.<sup>13,14,33,39,48</sup> Unclear regulations that exist worldwide, result in delay and restrictions to abortion services, including TOP for FFA.<sup>33,47,49</sup> To reduce delay and restrictions, Ireland's interim TOP for FFA guidelines transitioned from recommending that decisions on the fatality of a condition be made by majority consensus among MDT<sup>44</sup> members to recommending that MDT discussions are important but responsibility lies with the two certifying medical practitioners.<sup>16</sup> Over half of the FMS in this study found MDT discussions useful in determining whether a condition met the requirements for TOP. It is noteworthy, that the majority who benefitted from MDT discussions reported good institutional support. A MDT approach may be beneficial where clinicians receive organisational support and respect but can impede delivery of care where clinicians are undermined and unsupported.<sup>13</sup>

The psychological impact of working with perinatal and neonatal death experienced by the participants and the need for institutional and collegial support is documented in previous research.<sup>26, 51,58</sup> However, abortion is controversial and divisive, and conflict between colleagues can disrupt the sense of belonging in their professional group<sup>59</sup> as identified within this study. This is not isolated to the Irish experience, as UK Obstetricians associate more positive experiences when their decision-making is supported by a team with shared values, reducing isolation and vulnerability associated with potential legal challenges.<sup>39</sup> FMS would potentially benefit from the implementation of a structured collegial support system to reduce their feelings of disapproval from colleagues, assisting with clinician burnout, well-being and job satisfaction.<sup>26,55,56</sup> Despite the emotional impact, participants gained satisfaction in supporting women. This sense of fulfilment and source of strength from supporting parents are reflective of previous research.<sup>40,52,53,59,60</sup>

## Conclusion

The legal right to abortion does not automatically ensure the provision of appropriate abortion care. Our study identified challenges regarding the suitability of the Irish legislation for TOP for FFA and its rapid introduction into clinical practice. It advocates for the abolishment of the retained criminal liability attached to the legislation and the need for legislators to listen and trust FMS in their expert management of pregnancies affected by FFA. This study suggests the need for more research on institutional support for service providers to be undertaken. The challenges FMS encounter when managing pregnancies diagnosed with FFA illustrates the importance of institutional support and the need for healthcare management to support FMS in the provision of a new service.

### **Disclosure of interests:**

The authors have no relevant financial, personal, political, intellectual or religious interests to disclose. Completed disclosure of interest forms are available to view online as supporting information.

### **Contribution to authorship:**

All authors (SP, SM and KOD) have made substantial contributions to all of the following:

1. The conception and design of the study, acquisition of data, analysis and interpretation of data,
2. Drafting the article or revising it critically for important intellectual content, and
3. All approved the manuscript being submitted and take responsibility for its publication.

### **Details of ethics approval:**

Ethical approval for this study was granted by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (Ref. No. ECM 4 (gg) 12/02/19).

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## References

1. Coleman PK. Diagnosis of Fetal Anomaly and the Increased Maternal Psychological Toll Associated with Pregnancy Termination. *ISSUES IN LAW & MEDICINE*. 2015;30(1):3-23.
2. Irving C, Richmond S, Wren C, Longster C, Embleton ND. Changes in fetal prevalence and outcome for trisomies 13 and 18: a population-based study over 23 years. *J Matern Fetal Neonatal Med*. 2011;24(1):137-41.
3. Aite L, Zaccara A, Mirante N, Nahom A, Trucchi A, Capolupo I, et al. Antenatal diagnosis of congenital anomaly: a really traumatic experience? . *Journal of Perinatology*. 2011;31:760-3.
4. Fleming V, Iljuschin I, Pehlke-Milde J, Maurer F, Parpan F. Dying at life's beginning: Experiences of parents and health professionals in Switzerland when an 'in utero ' diagnosis incompatible with life is made. *Midwifery*. 2016;34:23-9.
5. Benute GRG, Nomura RMY, Liao AW, Brizot MdL, de Lucia MCS, Zugaib M. Feelings of women regarding end-of-life decision making after ultrasound diagnosis of a lethal fetal malformation. *Midwifery*. 2012;28(4):472.
6. Centre for Reproductive Rights. UN Human Rights Committee Asserts that Access to Abortion and Prevention of Maternal Mortality are Human Rights <https://reproductiverights.org/press-room/un-human-rights-committee-asserts-access-abortion-and-prevention-maternal-mortality-are2018>
7. Centre for Global Justice. UPR Mid-Term Submission to the UN Human Rights Council [https://www.ohchr.org/\\_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/UPR/NGOsMidTermReports/GlobalJusticeCenter\\_USA.docx&action=default&DefaultItemOpen=12018](https://www.ohchr.org/_layouts/15/WopiFrame.aspx?sourcedoc=/Documents/HRBodies/UPR/NGOsMidTermReports/GlobalJusticeCenter_USA.docx&action=default&DefaultItemOpen=12018)
8. United Nations of Human Rights. States must act now to allow safe, legal abortions for women and girls, say UN rights experts <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=23646&LangID=E2018>
9. Centre for Reproductive Rights. *Abortion Worldwide : 20 Years of Reform*. New York 2014.

10. United Nations Population Fund. International Conference on Population and Development Programme of Action: Twentieth Anniversary Edition. In: United Nations Population Fund, editor.: New York; 2014.
11. McCarthy J, O'Donnell K, Campbell L, Dooley D. Ethical arguments for access to abortion services in the Republic of Ireland: recent developments in the public discourse. *Journal of Medical Ethics*. 2018;44(8):513-7.
12. Government of Ireland. Eight Amendment of the Constitution Act, 1983. 1983.
13. Donnelly M, Murray C. Abortion care in Ireland: Developing legal and ethical frameworks for conscientious provision. *International Journal of Gynecology & Obstetrics*. 2020;148(1):127-32.
14. Taylor M, Spillane A, Arulkumaran SS. The Irish Journey: Removing the shackles of abortion restrictions in Ireland. *Best Practice & Research Clinical Obstetrics & Gynaecology*. 2020;62:36-48.
15. House of the Oireachtas. Health (Regulation of Termination of Pregnancy) Act 2018. Ireland 2018.
16. Institute of Obstetrics and Gynaecology and Royal College of Physicians of Ireland. Interim clinical guidance on pathway for management of fatal fetal anomalies and/or life-limiting conditions during pregnancy: Termination of pregnancy. Dublin, Ireland 2020.
17. Clarke V, Braun V. Teaching thematic analysis. *PSYCHOLOGIST*. 2013;26(2):120-3.
18. Holloway I, Galvin K. Qualitative research in nursing and healthcare. Fourth ed. Chichester, West Sussex, UK; Ames, Iowa; John Wiley & Sons Inc; 2017.
19. Power S, Meaney S, O'Donoghue K. Education priorities for voluntary organisations supporting parents experiencing perinatal loss: a Delphi survey. *International Journal of Palliative Nursing*. 2020;26(4).
20. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology*. 2006;3(2):77-101.



21. Braun V, Clarke V. Reflecting on reflexive thematic analysis, *Qualitative Research in Sport, Exercise and Health*. 2019; 11(4):589-597.
22. Egan H, Keyte R, McGowan K, Peters L, Lemon N, Parsons N, Meadows S, Fardy T, Singh P, Mantzios M. 'You Before Me': A Qualitative Study of Healthcare Professionals' and Students' Understanding and Experiences of Compassion in the Workplace, Self-compassion, Self-care and Health Behaviours, *Health Professions Education*. 2019; 5:225–236.
23. Baillie J, Anagnostou D, Sivell S, Van Godwin J, Byrne A, Nelson A. Symptom management, nutrition and hydration at end-of-life: a qualitative exploration of patients', carers' and health professionals' experiences and further research questions, *BMC Palliative Care*. 2018; 17:60.
24. Nowell LS, Norris JM, White DE, Moules NJ. Thematic Analysis: Striving to Meet the Trustworthiness Criteria, *The International Journal of Qualitative Methods*. 2017; 16(1):1-13.
25. Braun V, Clarke V. To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*. 2019; DOI: 10.1080/2159676X.2019.1704846.
26. McNamara K, Meaney S, O'Donoghue K. Intrapartum fetal death and doctors: a qualitative exploration. *Acta Obstetrica et Gynecologica Scandinavica*. 2018;97(7):890-8.
27. Cullen P. National Maternity Hospital orders review into abortion. *The Irish Times*. 2019.
28. Luce A, Cash M, Hundley V, Cheyne H, van Teijlingen E, Angell C. "Is it realistic?" the portrayal of pregnancy and childbirth in the media. *BMC pregnancy and childbirth*. 2016;16(1):40.
29. Bick D. Media portrayal of birth and the consequences of misinformation. *Midwifery*. 2010;26(2):147-8.
30. Power S, Meaney S, O'Donoghue K. The incidence of fatal fetal anomalies associated with perinatal mortality in Ireland. *Prenatal diagnosis*. 2020.

31. Wilkinson D, de Crespigny L, Xafis V. Ethical language and decision-making for prenatally diagnosed lethal malformations. *SEMINARS IN FETAL & NEONATAL MEDICINE*. 2014;19(5):306-11.
32. Dommergues M, Mandelbrot L, Mahieu-Caputo D, Boudjema N, Durand-Zaleski I, foetale ICIG-Cdm. Termination of pregnancy following prenatal diagnosis in France: how severe are the foetal anomalies? *Prenatal diagnosis*. 2010;30(6):531.
33. Orr J. *Abortion wars: The fight for reproductive rights*. 1<sup>st</sup> Ed. Bristol: Policy Press; 2017.
34. Lotto R, Smith LK, Armstrong N. Clinicians' perspectives of parental decision-making following diagnosis of a severe congenital anomaly: a qualitative study. *BMJ Open*. 2017;7(5).
35. Garne E, Khoshnood B, Loane M, Boyd PA, Dolk H, Grp EW, et al. Termination of pregnancy for fetal anomaly after 23 weeks of gestation: a European register-based study. *BJOG: An International Journal of Obstetrics & Gynaecology*. 2010;117(6):660-6.
36. Hayes-Ryan D, McNamara K, Russell N, Kenny L, O'Donoghue K. *Maternity Ultrasound in the Republic of Ireland 2016; A Review*. Irish Medical Journal. 2017.
37. Royal College of Obstetricians and Gynaecologists. *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales REPORT OF A WORKING PARTY*. United Kingdom: Royal College of Obstetricians and Gynaecologists; 2010.
38. Department of Health and Social care. *Abortion Statistics, England and Wales: 2018*. UK. 2019.
39. 28. Fay V, Thomas S, Slade P. Maternal–fetal medicine specialists' experiences of conducting feticide as part of termination of pregnancy: a qualitative study. *Prenatal Diagnosis*. 2016;36(1):92-9.
40. Farsides B, Williams C, Alderson P. Aiming towards “moral equilibrium”: health care professionals' views on working within the morally contested field of antenatal screening. *Journal of Medical Ethics*. 2004;30(5):505-9.

41. Crowe L, Graham RH, Robson SC, Rankin J. Negotiating acceptable termination of pregnancy for non-lethal fetal anomaly: a qualitative study of professional perspectives. *BMJ Open*. 2018;8(3).
42. Habiba M, Da Fre M, Taylor DJ, Arnaud C, Bleker O, Lingman G, et al. Late termination of pregnancy: a comparison of obstetricians experience in eight European countries. *BJOG: An International Journal of Obstetrics & Gynaecology*. 2009;116(10):1340-9.
43. World Health Organization and Department of Reproductive Health and Research. Safe abortion: technical and policy guidance for health systems. 2nd Ed. Geneva. 2012.
44. BBC News. Abortion: Assembly to debate recent changes to NI laws. Accessed at: <https://www.bbc.com/news/uk-northern-ireland-52878836>. 6<sup>th</sup> June 2020; 2020.
45. Pocklington D. Abortion law – Northern Ireland. Cardiff: Newstex; 2019
46. Savage W. Debate: Will abortion law in Northern Ireland finally move into the 21<sup>st</sup> century? *Public Money & Management*. 2019: 1-2.
47. Berer M. Abortion Law and Policy Around the World: In Search of Decriminalization. *Health and Human Rights*. 2017;19(1):13-27.
48. Chavkin W, Stifani BM, Bridgman-Packer D, Greenberg JMS, Favier M. Implementing and expanding safe abortion care: An international comparative case study of six countries. *International Journal of Gynecology & Obstetrics*. 2018;143(S4):3-11.
49. Albaladejo A. A “Witch Hunt Against Poor Women”: Across the Americas, Abortion laws are Harming Health and Security. *World Policy Journal*. 2016;33(4):26-34.
50. Institute of Obstetrics and Gynaecology and Royal College of Physicians of Ireland. Interim clinical guidance on pathway for management of fatal fetal anomalies and/or life-limiting conditions during pregnancy: Termination of pregnancy. Dublin, Ireland 2019.

51. Heazell AEPD, Siassakos DMD, Blencowe HM, Burden CMD, Bhutta ZAP, Cacciatore JP, et al. Stillbirths: economic and psychosocial consequences. *Lancet, The*. 2016;387(10018):604-16.
52. Ellis A, Chebsey C, Storey C, Bradley S, Jackson S, Flenady V, et al. Systematic review to understand and improve care after stillbirth: a review of parents' and healthcare professionals' experiences. *BMC pregnancy and childbirth*. 2016;16(1):16.
53. Shorey S, André B, Lopez V. The experiences and needs of healthcare professionals facing perinatal death: A scoping review. *International Journal of Nursing Studies*. 2017;68:25-39.
54. Nuzum D, Meaney S, O'Donoghue K. The impact of stillbirth on consultant obstetrician gynaecologists: a qualitative study. *BJOG*. 2014;121(8):1020-8.
55. West CP, Dyrbye LN, Rabatin JT, Call TG, Davidson JH, Multari A, et al. Intervention to Promote Physician Well-being, Job Satisfaction, and Professionalism: A Randomized Clinical Trial. *JAMA Internal Medicine*. 2014;174(4):527-33.
56. West CP, Dyrbye LN, Erwin PJMLS, Shanafelt TDP. Interventions to prevent and reduce physician burnout: a systematic review and meta-analysis. *Lancet, The*. 2016;388(10057):2272-81.
57. Steen SE. Perinatal death: bereavement interventions used by US and Spanish nurses and midwives. *International Journal of Palliative Nursing*. 2015;21(2):79-86.
58. Puia DM, Lewis L, Beck CT. Experiences of Obstetric Nurses Who Are Present for a Perinatal Loss. *Journal of Obstetric, Gynecologic & Neonatal Nursing*. 2013;42(3):321-31.
59. Britton LE, Mercier RJ, Buchbinder M, Bryant AG. Abortion providers, professional identity, and restrictive laws: A qualitative study. *Health Care for Women International*. 2017;38(3):222-37.
60. Chiappetta-Swanson C. Dignity and Dirty Work: Nurses' Experiences in Managing Genetic Termination for Fetal Anomaly. *Qualitative Sociology*. 2005;28(1):93-116.

Table 1: Years' experience working in fetal medicine

Participant	Years
1	4 - 14 years
2	4 - 14 years
3	4 - 14 years
4	15 - 30 years
5	15 - 30 years
6	4 - 14 years
7	15 - 30 years
8	15 - 30 years
9	15 - 30 years
10	4 - 14 years

Table 2: Themes and subthemes

Theme	Subtheme
<b>Not fatal enough</b>	Fear of getting it wrong Legislation is difficult Not clearly fatal but clearly awful is challenging
<b>Interactions with colleagues</b>	Teamwork Conflict Organisational culture
<b>Support for pregnant women</b>	Warning shot Health Literacy How much support is enough
<b>Internal conflict and emotional challenges</b>	Internal conflict Psychological Impact Positive feelings

Table 3: Direct Quotes

**Not fatal enough:**

*people are nervous about being that first person who might be prosecuted... when people have to put their name on something or their head is on the line there is a fear for sure*

*Week one of the new legislation, it was fetal medicine reports on the front page of the newspaper being read out in the Dáil, that is at the back of your mind*

*... the litigious environment that we work in and the medical legal aspects of working in this area have been shown... difficult cases last year and cases that have made it into the media and the cases that will go to court. And so we are not protected in our practicing in any way*

*none of us want to be in a situation where we thought, ah sure deliver and then the baby is alive six weeks later and there's all the issues that go with that*

*from a very kind of selfish perspective. And you'd worry about whether if I do get it wrong and what if we, you know, induce this baby at term and actually it lives for six weeks because there's always an outlier*

*I think that my biggest challenge is the understanding of what is covered under the legislation. I think that it is more what is covered and I think people thought that if we had termination of pregnancy introduced in Ireland that nobody would ever have to travel to the UK for termination of pregnancy again. And that is not the case*

*But it's quite strict in terms of what is offered. You know, and it's purely almost certain. And, what's the word? in reasonable faith, So the bar is set high. So there are many patients that are still travelling to the UK*

*'Oh I have seen a case where the baby lived' so it is almost if somebody has seen a baby survive something, other people are afraid to appear as pro-abortion*

*Non-fatal is a whole different ball game. You have got a baby with life limiting, with a poor quality of life which may limit the duration but it is certainly going to have an impact on the parents and the other children in the family and the rest of their lives. That is a much bigger deal and I feel for those parents now, I feel they are completely and utterly abandoned really by the system*

**Interactions with colleagues:**

*The midwives are very experienced and comfortable which is probably the most important thing*

*I would usually involve the bereavement midwives early and I think that is really helpful... it would really fall on the bereavement midwives a lot*

*...obviously the national and international meetings are very good on keeping up to date. And the teams here have been very supportive amongst each other*

*...so like peer support with my colleagues is very important to me and that I suppose locally. And maybe more broadly nationally, talking about these things in an informal setting because it isn't something that is necessarily easy to talk about with certainly non-medical people...*

*It's actually got infinitely harder since January a year ago (when TOP for FFA was implemented)*



Table 4: Direct Quotes

**Support for pregnant women:**

*I don't really like doing it if they don't have someone with them so it can be a little bit less, it is usually bare diagnosis and would you like to come back with somebody with you... I feel this is too much for one person. ... I think patients as well, they listen to that cue so when the sonographer is saying you are going to see the doctor, you need to bring someone with you. For the majority of them that is a sign.*

*And then we arrange for them then to come into the hospital and I...I actually find that, that they have time, and we may see them the next day or the following day, it is usually within 48 hours, but that they have processed and started to think about what it means for them and their baby and their pregnancy.*

*It (diagnosis) would always be in person. I never do anything over the phone... I would always bring people back in.*

*The first was to be compassionate, honest, open. You kinda judge things depending on how bright, intelligent, how supportive they are at the time.*

*We tell them there is open access, if they ring in and they have a problem they come into us. So they bypass the normal clinics after that.*

*I think ultimately it is a shit time and it is a lonely time for them and often it is them and their partner dealing with it. I honestly don't know how much support is enough. (a FMS who offers open access to parents)*

*I don't think it's (support) adequate, but I think it's adequate in what we can offer.*

*We kind of give them the option to come back for a six week check with us, sometimes they don't necessarily come back to see me, they might see one of the midwives, it just depends on if there is any complications, if they want to talk about the future... There are some couples that you do get very attached to.*

*I realising now that that's good to be a part of my role. But just to get to follow them up and meet you back afterwards. And and again, that's quite useful for them because they're at a stage where they can think about planning another pregnancy sometimes*

### **Internal conflict and emotional challenges:**

*To be honest, I struggled with this quite a bit. But I've seen so many women traumatised in this situation, the fatal fetal and lethal, LLCs (life-limiting conditions), that I think the right thing for that group is to offer this treatment in Ireland*

*It is always very sad and emotional, it is difficult but something that I guess I have been doing for a long time and I am aware that I am doing it for a long time. It doesn't necessarily mean it is easier, it is always very sad*

*I remember getting sick out in the corridors afterwards because I thought it (feticide) was such an awful procedure and so dreadful*

*You have to see the positive in it otherwise you would drive yourself mad*

*Ultimately you feel some degree of positivity if you get people through. And then if you see them back in another pregnancy and they've made it and so on, that's good*